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New ONC Initiative Tackles Data Segmenting in HIE

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One of the most challenging issues in electronic health information exchange (HIE) relates to tagging and separating certain pieces of health data from others in an electronic health record. There are myriad reasons why separating different types of health information is important to HIE, including enabling consumers to exert greater control over who sees their health information, but doing so can be difficult.

To overcome existing obstacles, the Office of the National Coordinator for Health IT recently began a new [Data Segmentation Initiative](#). The initiative will develop standards to electronically tag and separate sensitive health information.

Background on Data Segmentation

In a white paper commissioned by ONC, researchers from the George Washington University and AcademyHealth describe data segmentation as "the process of sequestering from capture, access or view certain data elements that are perceived by a legal entity, institution, organization or individual as being undesirable to share."

In other words, data segmentation allows health care providers, consumers and other stakeholders to choose:

- What specific pieces of health information to share (ranging from discrete pieces to whole categories of information);
- Who can access specific pieces of health information;
- Under what circumstances different stakeholders can access the information (e.g., for treatment or research); and
- For what length of time the information can be accessed.

Data segmentation is important for at least two reasons. First, it can help stakeholders comply with federal and state laws that protect the confidentiality of consumers' health information. Some of these laws provide special protection for sensitive health information, which can include genetic, mental health, substance abuse and HIV/AIDS-related information. This special protection often includes requiring health care providers to obtain a patient's written consent before disclosing such information.

Data segmentation allows health care providers to:

- I. Separate sensitive health information from general medical information; and
- II. Withhold the sensitive health information from exchange until they obtain any special consent that may be required by law.

Other state laws extend special protection to information about health care services minors consented to without the involvement of a parent or guardian. In many cases, only the minor (not a parent or guardian) can consent to the disclosure of this information. Unless a health care provider can segment in the EHR the information controlled by the minor from information controlled by the minor's parent, the health care provider may be unable to exchange such information electronically while complying with state minor-consent laws.

Second, based on their own preferences or values, consumers may want to keep confidential certain information that is not otherwise considered sensitive by law. Data segmentation enables consumers to identify certain pieces of health information as sensitive and to ascribe special privacy preferences to that

There are, however, technical challenges that make data segmentation difficult. To be segmented, electronic health information must be structured and coded so that computers can distinguish between different types of health information (e.g., general medical information versus information about HIV/AIDS treatment) and consistently treat them separately. Today, much electronic health information is unstructured, having been entered into electronic systems using free-text fields that computers cannot easily segment.

Factors Influencing ONC's Development of the Data Segmentation Initiative

The health IT community has long recognized the need to identify and apply special protections to information that consumers deem sensitive, and a number of factors likely influenced ONC's development of the Data Segmentation Initiative.

In 2006, for example, the National Committee on Vital and Health Statistics -- an advisory body to the federal government on health data, statistics and national health information policy -- recommended that the government assess the "desirability and feasibility" of allowing individuals to control access to their electronic health information when it is disclosed through the Nationwide Health Information Network.

Congress included similar directions in the HITECH Act, requiring the Health IT Policy Committee created by HITECH to advise ONC on a policy framework for nationwide HIE, and to recommend technologies that protect the privacy of health information in an EHR, "including for the segmentation and protection from disclosure of specific and sensitive individually identifiable health information with the goal of minimizing the reluctance of patients to seek care ... because of privacy concerns ..."

A December 2010 report from the **President's Council of Advisors on Science and Technology** also encouraged the federal government to enable more granular protection of health information privacy. Specifically, the report recommended the use of a universal electronic exchange language based on tagged data elements, including use of metadata to tie consumer privacy preferences to specific pieces of health information. According to PCAST, health information should be separated into the smallest individual pieces possible for HIE. These pieces of health information should then each be accompanied by metadata (i.e., data about data) that describes if and how each piece of health information can be shared, among other things.

Goals and Operations of the Data Segmentation Initiative

The overarching goal of the Data Segmentation Initiative is to produce a pilot project that will allow health care providers to share certain pieces of information in an EHR but not others. Thus, the initiative is designed to facilitate electronic HIE that complies with the country's patchwork quilt of health information privacy laws and enables stakeholders to exert more control over how health information is shared.

Among other activities, the initiative will build on the PCAST recommendations for use of metadata tags and will test metadata-related standards recommended by the Health IT Standards Committee, which was established under HITECH to advise ONC on standards, implementation specifications and certification criteria for electronic HIE. The **committee's recommended standards** relate to three different types of metadata:

- Patient identity metadata (e.g., patient name and date of birth);
- Provenance metadata (e.g., data relating to who accessed the health information and when); and
- Privacy metadata (e.g., data describing the privacy preferences ascribed to the health information).

ONC released an **advanced notice of proposed rulemaking** requesting public comment on these metadata standards on Aug. 9. Comments were due Sept. 23.

ONC has said that the Initiative will focus on at least two particularly thorny use cases:

- One related to the sharing of information about patients in federally assisted alcohol or drug abuse

- treatment programs, which is subject to special protection under federal regulations; and
- Another related to information about a particular health care service for which a patient pays in full and which the patient would like to restrict from disclosure to his or her health plan.

It is important to note that while data segmentation holds particular promise for ensuring health information privacy, the electronic capture and separation of different types of health information also can help enable other valuable health care activities, including those relating to quality improvement, public health and comparative effectiveness research.

The Data Segmentation Initiative, which officially launched in October, is part of ONC's larger Standards and Interoperability Framework. Participants will meet frequently by webinar and teleconference and will use a Wiki page to facilitate their work. ONC is seeking the participation of a wide range of stakeholders, including health IT vendors, health systems, standards development organizations, patient advocates and the general public.

Interested parties can choose to participate as an "initiative committed member" or an "other interested party," which generally requires less commitment. More information about participating in the initiative and the process for signing up is [available here](#).

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